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ABSTRACT

Three issues of this newsletter include articles on and news items related to deaf-blindness. Articles include the following: "Research-to-Practice: Bridging the Gap between Research and Demonstration Projects and Practical Needs of Parents and Educators" (Harvey Mar and Nancy Sall); "Syndromes, Behavior, and Educational Intervention" (J. P. M. van Dijk and Catherine Nelson); and "Issues and Concerns Related to Inclusive Education for Students Who Are Deaf-Blind: Findings of the Task Force of a Model Demonstration Project" (Terry Rafalowski Welch and Lori Goetz). Other items include comments by the editor, summaries of current projects, a description of DB-LINK (The National Information Clearinghouse on Children Who are Deaf-Blind), a description of the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind, conference announcements, letters to the editor, and summaries of relevant books. (Major articles contain references.) (DB)

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ED 415 612

Deaf-Blind Perspectives

Volume 4, Issue 1

Fall 1996

Research-to-Practice: Bridging the Gap Between Research and Demonstration Projects and Practical Needs of Parents and Educators

Harvey Mar
Nancy Sall

DB-LINK expresses appreciation to Charles Freeman, Severe Disabilities Branch, Office of Special Education Programs for providing information about the federal grants program.

Since 1978, the U. S. Department of Education has provided continuous support for research-and-demonstration projects to improve practices and techniques in educating children and youth with deaf-blindness. Beginning with three model projects, the federal program steadily expanded so that by the mid-1980s more than 30 special projects were being funded each year. The overall mission of the Department of Education has been to identify innovative and effective educational approaches. To that end, more than $54 million has been spent on demonstration, training, research, and systems-change projects since the program's inception.

What have we learned from these special projects? What has been the impact on educational practices? How have the findings, resources, and materials from these projects been put to use? The purpose of this article is twofold. First, it is intended to introduce DB-LINK's new Research-to-Practice Initiative (RPI), which is designed to bridge the gap between research and demonstration projects and the people who stand to benefit most from their findings. Second, it endeavors to inform the reader about a number of recent projects that may be useful to the practioner; these projects are listed in the second portion of this article.

We know that information generated by research and demonstration projects is *available*, but there are many concerns that it is not readily *accessible* to consumers, family members, and educators. For instance, findings may be reported in research journals that do not go beyond a limited professional audience. Often, materials and resources do not exist in forms that are "user friendly" to parents and teachers. Also, workshops or seminars in which new knowledge is presented may be limited to the schools or geographic regions where these presentations are made. Perhaps the greatest concern is that the mission of the researcher often differs from that of the teacher or parent, who may not perceive a particular project as being directly relevant to a student's day-to-day needs.

The RPI is taking several steps to bridge this gap between researchers and those who need this information. DB-LINK proposes an action plan that involves close collaboration with directors of research-and-demonstration and other special projects on deaf-blindness. Specific objectives and activities of the RPI are to:

Conduct periodic reviews of current and recent federally supported research-and-demonstration projects on deaf-blindness.

DB-LINK has contacted project directors and project coordinators of recently funded projects on deaf-blindness to obtain information about their findings and the availability of their resource mate-

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rials. A brief summary of this information is included in this report. In future issues of *Deaf-Blind Perspectives*, individual projects will be highlighted with emphasis on practical implications to consumers, family members, service providers, and educators.

Identify important project findings and interventions that have practical application in home, classroom, and/or community environments.

Many important interventions, teaching strategies, and observations are buried within project reports. Furthermore, projects may produce information or materials that are not widely circulated. As part of the RPI, DB-LINK will make every effort to access and review technical reports, journal articles, conference proceedings, professional papers, newsletters, handouts, and other resources to identify potentially effective practices and resources. In the process, DB-LINK will work cooperatively with project directors to develop user-friendly forms of this information (e.g., fact sheets, pamphlets).

Share Research-to-Practice findings with the single and multi-state 307.11 projects.

As coordinators of deaf-blind education services, staff on state and multi-state 307.11 projects have the responsibility to ensure that educators in their jurisdictions use state-of-the-art procedures. The Research-to-Practice model will provide 307.11 staff with this information. Each 307.11 coordinator will be able to share this information with direct service staff through inservice trainings, newsletters, technical assistance, etc.

Share outcomes of the important project findings with NTAC (National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind).

NTAC personnel impact hundreds of professionals across the nation each year who in turn provide direct service to children and young adults who are deaf-blind. Keeping NTAC staff informed of the latest usable research will expedite the transference of these findings to practicing professionals. Armed with knowledge of the latest research, NTAC staff will be able to coordinate the elevation of research to practice by making findings available not only to educators via the state 307.11 projects but also to other professionals through cooperating agencies (e.g., vocational rehabilitation, community colleges, independent living centers) serving young adults who are deaf-blind.

Share pertinent findings with The National Family Association of the Deaf-Blind (NFADB) and local family units.

Many of the research-to-practice findings will also be helpful to parents and family members of children and young adults who are deaf-blind. By sharing the information with NFADB, it will in turn be made available to parents--usually the premier advocates in the lives of young people who are deaf-blind.

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Deaf-Blind Perspectives considers all unsolicited manuscripts and employs an anonymous review process. Manuscripts should adhere to *American Psychological Association* standards. Send both a printed copy and a disk copy (preferably DOS format) to:

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Communicate with directors and staff of research and demonstration projects about requests for information from family members, consumers, and educators that pertain to their areas of study.

DB-LINK receives many requests for information pertaining to the educational, social, and health issues of people who are deaf-blind. By alerting project directors to these general informational needs, mutual gains can be realized. Future projects may better understand and address the specific needs of individuals who are deaf-blind, their families, and the people who work with them. This, in turn, may serve to promote the development of more useful materials and resources.

Assist projects to identify a wide range of outlets for the dissemination of their findings, products, materials, and resources, including information clearinghouses, parent organizations, consumer groups, and professional organizations.

One concern which led to the formation of RPI is the belief that projects can-- and must--promote effective educational practices through implementation of a well-developed dissemination plan. The RPI calls for DB-LINK and project directors to work together to promote the visibility, permanence, accessibility, and replicability of positive outcomes and material resources.

Serve to promote public awareness of current or promising approaches, materials, and results from research and demonstration projects on deaf-blindness.

Findings and resources from special projects often take several years before reaching the targeted audiences. For example, research may be reported in a journal or a final report long after the project has been completed. The RPI aims to reduce the lag time between research findings and their practical applications by publicizing new information as soon as it becomes available.

Current Research and Demonstration Projects

It is interesting to compare recent research and demonstration projects with those funded a decade ago. Certainly, the overall mission of the grants programs in deaf-blindness has been consistent: namely, to "demonstrate innovative and effective approaches" to the education of children and youth who are deaf-blind (Federal Register, July 22, 1985). So, too, have the federal priorities--areas of special concern--remained consistent. Ten years ago, projects focused on such critical areas as communication skills, teacher training, vocational and transitional services, and increasing parental involvement in the educational process. Obviously, these and other areas are still priorities today.

However, the past ten years have witnessed several substantial differences in how we conceptualize these priority areas. One has been the shift in emphasis from designing innovative educational practices in "least restrictive" or "least segregated" environments to "fully inclusive" or "fully integrated" educational and community settings. The change in terminology is not just semantic. It reflects the *expectation* that children and youth who are deaf-blind be offered and/or provided opportunities and support to participate fully in the schools and programs within their communities. Another change has been the extension of projects on communication skills to emphasize social interactions and relationships. Increasingly, communication training materials and methods, such as the use of symbol systems, tactual signing, and augmentative or assistive devices, are being developed and evaluated in the contexts of natural parent-child interactions and peer relationships. We have recognized that communication skills cannot be separated from social skills, and that they are best taught and studied amidst the complexities of the real social world.

A third change has been in the scope of today's projects. A long-standing aim of the federal grants program has been to increase local or state "capacity," which refers to the building up of personnel, material, and informational resources in the regions in which projects on deaf-blindness are conducted. A quick glance below will show that many current projects also have national impact through their creation of task forces, advisory boards, and consortia involving parents, consumers, and professionals from around the country.

Summary

The descriptions of the projects below serve to highlight some of the research-and-demonstration topics of current concern. Each project has tremendous potential to identify effective practices, lessons learned, challenges, interventions, and insights about the education of children and youth who are deaf-blind. DB-LINK's research-to-practice initiative seeks to help all projects realize their potential to provide information and resources having practical significance, direct and immediate application, and positive outcomes for the students, their families, educators, and service providers.

A Sampling of Current Projects

Current special projects on deaf-blindness are presented here according to their areas of investigation. These include: inclusion, communication and technology, early intervention, professional training and development, lifestyle planning, problem-solving skills, and social relationships. The project directors or coordinators were contacted by telephone to obtain information about useful findings and products available for parents and practitioners.

Inclusion of Students with Deaf-Blindness

Two projects have recently been funded which fall under the umbrella of inclusion. A project called **Full Inclusion Program for Students with Deaf-Blindness** is based at San Francisco State University and is directed by Dr. Lori Goetz. This model and demonstration project has identified and worked with six students who are deaf-blind and who attend full-time inclusive education programs. In addition, a national task force for this project was organized to pursue specific content problem areas and potential solutions, as well as to analyze effective practices. Task force members are also responsible for presenting case studies of inclusive education programs from around the country. The project provides direct support, training, and/or consultation to the students with deaf-blindness, their peers, and educators in fully inclusive programs in California. The project emphasizes the importance of a cohesive team and collaboration among all parties. Dr. Goetz remarked that one of the first questions to ask in developing an inclusive program is, "How do you make a team work in a functional and positive way?" The project is developing a series of products for parents and educators, including an overview of inclusive education practices involving students who are deaf-blind and a narrative of case studies from around the country. This review will be available Fall 1996 through the California Research Institute.

For further information, Dr. Goetz can be contacted at:

San Francisco State University
1640 Holloway Avenue
San Francisco, CA 94132
415-338-1306
e-mail address: lgoetz@sfsu.edu.

The second project within this category is entitled **Related Services Research to Support the Education of Students with Deaf-Blindness** and is based at the University of Vermont. Dr. Michael Giangreco is the project director. The project seeks to implement and evaluate a set of ten specific guidelines to help educational teams make decisions about how best to deliver related services (e.g., therapies) for students who are deaf-blind in inclusive education programs. The process is called VISTA (Vermont Interdependent Services Team Approach). The project is studying how the application of VISTA affects the provision of related services to students (e.g., location of services, educational relevance, improved knowledge of team members). The VISTA process is described in a manual published by Paul H. Brookes Publishing Co. (Vermont Interdependent Services Team Approach: A Guide to Coordinating Educational Support Services, 1996, 176 pages, $26.00, 1-800-638-3775.) Additional information about this project, including a series of five "quick guides" for educating students with deaf-blindness and other severe disabilities, can be obtained from Dr. Giangreco at:

University of Vermont
499C Waterman Building
Burlington, VT 05405
802-656-1144.
http://www.uvm.edu~uapvt/RSRP.html (*Includes specific research questions, a brief description of VISTA, and numerous listings of products including articles and abstract.*)

Communication and Technology

There is currently one research project on communication and technology. **Use of FM Systems with Children who are Deaf-Blind**, directed by Dr. Barbara Franklin at San Francisco State University, studies the impact of FM systems on the development of communication skills. An FM system consists of a microphone which is worn by the person speaking (e.g., teacher, classmate, parent) and a receiver which is worn by the student with hearing impairment. This project examines how new technologies in FM systems affect social interactions between students who are deaf-blind and their typical peers. Research methods include observations of students using FM systems in integrated settings and interviews of teachers, peers, families, and individuals with deaf-blindness. The project also provides inservice training for teachers and family members on the use of FM systems. Dr.

Franklin notes that FM technology has expanded since the development of new, compact, behind-the-ear units. A training manual and videotape on the benefits of this technology are currently being developed. Dr. Franklin can be contacted at:

San Francisco State University
Department of Special Education
1600 Holloway Avenue
San Francisco, CA 94132
415-338-1249.

Early Intervention

Two projects focus on early intervention. Both are conducted at California State University at Northridge. **Project PLAI: Promoting Learning, Activities, and Interaction in Infants who are Deaf-Blind** is a research validation project on infant-caregiver interactions, co-directed by Drs. Deborah Chen and Michele Haney. Dr. Chen states that the primary goal of the project is to facilitate healthy relationships between family members and infants with deaf-blindness. The project has developed a series of questionnaires for parents and early interventionists to gather information about early communication behaviors of infants with deaf-blindness. Infant-caregiver interactions are videotaped. This information is used to develop interactive games designed to increase positive interactions between infants and caregivers and to promote caregivers' sense of competence when interacting with infants who are deaf-blind. The project also conducts workshops and provides technical assistance to families and early intervention personnel. The questionnaires and curricular games are being field-tested for production in the Fall of 1997. Dr. Chen will present a paper on this project in December 1996 at the Division of Early Childhood Conference (DEC) in Phoenix.

The second project is called **Early Intervention Model Demonstration Network for Infants with Deaf-Blindness and Their Families**. This project, also directed by Dr. Deborah Chen, seeks to improve early intervention programs and services for infants and family members. The project has been working with six early intervention programs in which infants who are deaf-blind are enrolled. Early intervention teams endeavor to identify relevant intervention goals and activities that consider unique issues of deaf-blindness through a systematic Program Self Review. The project has also worked with families to identify useful materials. One outcome of the project has been the development of three videotapes on functional hearing and audiological assessment, functional vision assessment, and early communication behaviors. Discussion guides are currently being developed for the videotapes. The videotapes, discussion guides, and Program Self Review will be available in January of 1997. For additional information, contact Dr. Chen or Dr. Haney at:

California State University
Department of Special Education
18111 Nordhof Street
Northridge, CA 91330
818-885-4604 (Dr. Chen)
818-885-3874 (Dr. Haney).

Personnel Training and Professional Development

The Perkins National Deafblind Training Project: A Collaborative Model is directed by Marianne Riggio and coordinated by Dr. Barbara McLetchie of Perkins School for the Blind. The project was designed to address the concern that only about 6% of educators working with students who are deaf-blind have had specific training in deaf-blindness. The project has created a national consortium of experts in deaf-blindness on training needs of teachers; conducted a national survey to identify the most critical training needs; conducted eight summer institutes to train teachers of students who are deaf-blind, their parents, administrators, and other service providers; and developed a "standard of competencies"—the skills and knowledge that teachers need to work with students who are deaf-blind. The project is compiling and field-testing the set of teacher competencies, which will help define training standards for teachers. These will be available for dissemination September 1996. Ms. Riggio and Dr. McLetchie can be contacted for additional information at:

Perkins School for the Blind
125 N. Beacon Street
Watertown, MA 02172
617-972-7264 (Ms. Riggio)
617-972-7226 (Dr. McLetchie).

Lifestyle Planning

A project on **Services for Children with Deaf-Blindness: Lifestyle Planning and Enhancement** is directed by Dr. Norris Haring and coordinated by Dr. Lyle Romer of the University of Washington. The project is designed to develop, implement, and evaluate a set of procedures to improve the lifestyles and quality of educational services for individuals who are deaf-blind. "Lifestyle planning" is a process which identifies students' strengths, builds formal and informal supports

and networks, and prepares individuals for successful community living. The project has worked directly with many families by providing technical assistance. Project results suggest that such person-centered planning can have positive impact on the quality of IEPs (individualized educational programs), as well as on the students' social activities and interactions. The project also has trained nondisabled peers to communicate and interact more effectively with students who are deaf-blind. Subsequent observations indicate that rates of contact and the qualities of interaction improve between students with deaf-blindness and nondisabled peers. A chapter on lifestyle planning is presented in the book Welcoming Students Who Are Deaf-Blind Into Typical Classrooms, edited by Norris Haring and Lyle Romer (Paul H. Brookes Publishing Co., 1995, 480 pages, $35.00, 1-800-638-3775). An article on peer mediation training also appeared in the December 1995 issue of the professional journal *Education and Training in Mental Retardation and Developmental Disabilities*. For additional information, contact Dr. Norris Haring or Dr. Lyle Romer at:

University of Washington
Experimental Education Unit WJ-10
Seattle, WA 98195
206-543-8565 (Dr. Haring)
pager 360-786-2525 (Dr. Lyle Romer).

Problem-Solving Skills

One research project is studying how children with deaf-blindness learn to master their physical environments. A project entitled **Overcoming Helplessness: Hands-On Problem Solving Skills for Children with Deaf-Blindness** is collecting information from parents and teachers of children with deaf-blindness. The project is directed by Dr. Charity Rowland and coordinated by Philip Schweigert at Washington State University-Portland Projects in Portland, Oregon. Results will be used to develop a better understanding of how children with vision and hearing impairments come to know about their physical worlds. The project seeks to better describe how children learn to overcome barriers and obstacles, explore objects, use tools, construct objects, match one object to another, and search for and retrieve materials they desire. Results will be summarized for a journal article. In addition, assessment instruments for use in school and at home will be revised so that parents and teachers can monitor how children with deaf-blindness acquire problem-solving skills. A videotape will be made available which illustrates the assessment instrument. For more information, contact Dr. Charity Rowland at

Washington State University-Portland Projects
1818 S.E. Division
Portland, OR 97202
503-232-9145
e-mail address: rowland@vancouver.wsu.edu.

Social Relationships

Three research projects were recently completed on the social relationships and interactions of students who are deaf-blind. One project, Social Relationships of Children and Adolescents with Deaf-Blindness, was directed by Dr. Harvey Mar and coordinated by Nancy Sall at St. Luke's/Roosevelt Hospital in New York City. This project provided support and assistance to help increase social opportunities and interactions for ten students with deaf-blindness. Intervention activities were designed to increase teacher awareness of natural school-based opportunities for social interaction, promote increased parental involvement in creating social opportunities in their communities, increase peer involvement with the students, and support the establishment of socially integrated activities in schools. The project identified specific barriers which impeded social opportunities, as well as useful strategies to promote social interactions and relationships between students with deaf-blindness and their school peers. These are summarized in several products and materials, including the final report (available through DB-LINK or ERIC), a series of handouts entitled Notes for Educators Working with Students who are Deaf-Blind (available from the project coordinator or DB-LINK), an article entitled "Enhancing Social Opportunities and Relationships of Children Who are Deaf-Blind" in the May-June 1995 issue of *Journal of Visual Impairment and Blindness* (vol. 89) , and proceedings from a regional workshop on social relationships of children with deaf-blindness (soon to be available from the project coordinator). Parents may be interested in a brief summary of an interview study conducted on parental perceptions of the friendships and social activities of their children (*New York Parent Newsletter*, 1996, vol. VIII, available from New York Parent Network Inc., P.O. Box 423, Yonkers, NY, 10704). For further information about the project, contact Dr. Harvey Mar or Nancy Sall at:

St. Luke's/Roosevelt Hospital Center
1000 Tenth Avenue, Antenucci-9
New York, NY 10019
212-523-6280
e-mail addresses: hhm1@columbia.edu (Dr. Mar)
nsall@aol.com (Ms. Sall).

A second project, **Research on Social Relationships for Children and Youth with Deaf-Blindness**, was directed by Dr. Robert Horner and coordinated by Dr. J. Stephen Newton at the University of Oregon. The project examined stability of social relationships between persons with severe disabilities and members of their communities. Studies also examined ways to reduce barriers to social activities, train peers to become more socially competent during interactions, and enhance social support. Several different studies were published, including: "A Conceptual Model for Improving the Social Life of Individuals with Mental Retardation" in the December 1994 issue of *Mental Retardation*; "Factors Contributing to the Stability of Social Relationships Between Individuals with Mental Retardation and Other Community Members" in the December 1995 issue of *Mental Retardation*; and, "Social Skills and the Stability of Social Relationships Between Individuals with Intellectual Disabilities and Other Community Members" in *Research in Developmental Disabilities* (1996, vol. 17, issue 1). For additional information, Drs. Robert Horner and Steve Newton can be contacted at:

The Specialized Training Program
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University of Oregon
Eugene, OR 97403
503-346-2462 (Dr. Horner)
503-346-2470 (Dr. Newton)
e-mail address:
steve_newton@ccmail.uoregon.edu (Dr. Newton)

The **Friends for Life** project, directed by Dr. Norris Haring and coordinated by Dr. Lyle Romer at the University of Washington, was concerned with developing strategies and procedures to support meaningful friendships between children with deaf-blindness and their nondisabled peers. Findings from this project suggest that students with deaf-blindness have very low rates of contact with their peers in integrated settings and that relationships that do develop tend to be unstable and fleeting. For the answers to critical questions, such as how to increase the endurance of relationships, the project staff turned to peers for assistance. The project found that empowering peers proved more fruitful in creating meaningful and stable relationships than the use of adult-mediated strategies. Several professional articles were prepared from these studies including an article for the *TASH Newsletter* (February 1993) entitled "Julian's Transition: A Dream Team and Hard Work." A handout on simulation exercises, Assisting Young People to Meet their Peers Who are Deaf-Blind and information about journal publications are available through Dr. Norris Haring at:

University of Washington
Experimental Education Unit WJ-10
Seattle, WA 98195
206-543-8565.

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DB-LINK

The National Information Clearinghouse On Children Who Are Deaf-Blind

DB-LINK (The National Information Clearinghouse On Children Who Are Deaf-Blind) is pleased to announce notice of funding for the period 1996-1999. Round II, as we call it, will allow us to build upon our current efforts to expand and provide cost-free information related to children and youth (0-21) who are deaf-blind, their families, and the professionals who serve them. DB-LINK operates under the leadership and central management of the Teaching Research Division of Western Oregon State College.

Over the course of Round II, DB-LINK will:

- Maintain, expand, and disseminate information on deaf-blindness to all groups;
- Oversee the development of selected fact sheets and contribute to *Deaf-Blind Perspectives;*
- Develop and implement the Research-to-Practice Initiative (see article on page 1 of this issue);
- Work towards incorporating technology to complement existing information services including making our databases available via Internet, and online bibliographies;
- Work *with* 307.11 projects to facilitate information sharing; and
- Expand our existing linkages with consumer, family, and professional groups.

A core group of three agencies has been the backbone of DB-LINK since its inception in October of 1992: Helen Keller National Center, Perkins School for the Blind, and Teaching Research. These three agencies will continue to work in harmony to maintain a national clearinghouse that locates, or-

ganizes, manages, and disseminates information about deaf-blindness in areas that include: effective early intervention, special education, and general education practices; related medical, health, social, and recreational services; relevant legal issues; employment and independent living; post-secondary educational services; and information on the nature of deaf-blindness. Other cooperating agencies (American Association of the Deaf-Blind, National Family Association of the Deaf-Blind, for example) are currently involved with DB-LINK in a variety of contractual and less formal collaborations.

DB-LINK has developed and maintains multiple databases that include bibliographical as well as local, regional, national, and international resources that serve the target population. This information is disseminated to a wide audience including state-level service coordinators, other professionals, parents, employers, and members of the public via DB-LINK Information Specialists housed at the core agencies. An inquiry-response process tailored to the needs of the requestor utilizes a combination of traditional (toll-free voice/tty phones, hard-copy information packets, etc.) and electronic means (Internet, Worldwide Web, electronic bulletin boards, etc.) to disseminate information to consumers throughout the United States.

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We encourage you to copy and share information from *Deaf-Blind Perspectives*, but please provide appropriate citations.

NTAC

National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC)

Teaching Research Division of Western Oregon State College, and Helen Keller National Center are pleased to announce funding of the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC). The project is funded under the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Office of Special Programs. The primary mission of **NTAC** is (a) to assist states to improve the quality of existing placements and services for individuals (birth to age 28) who are deaf-blind, and (b) to increase the numbers of children, young adults, their families, and their service providers who will benefit from these services.

NTAC combines the vast resources, expertise and experience of two prominent agencies: Teaching Research and Helen Keller National Center. These two agencies have united in a national cooperative effort to furnish training and technical assistance to families, service providers, state agencies, and organizations responsible for the care and services of infants, young children, school-age children, and young adults who are deaf-blind. By partnering together, the consortium agencies bring years of successful technical assistance experience from the Teaching Research TRACES Project and the Helen Keller National Center - Technical Assistance Center.

NTAC will work with agencies and families within states through the provision of technical assistance to:

- "Facilitate long-range planning and development of collaborative partnerships among families, service providers, and agencies at the local, state, and regional levels;
- "Use "effective practices" and current research findings to enhance training opportunities for families and service providers to increase awareness, knowledge, and skills in meeting the unique needs of children and young adults who are deaf-blind;
- "Assist parents and family members in advocating for and participating in effective service delivery systems for the family member who is deaf-blind;

- "Assist young adults who are deaf-blind to promote self-advocacy and self-determination; and
- "Develop a nationwide database of demographic characteristics of infants through young adults who are deaf-blind.

NTAC is committed to using the most effective resources and approaches to assist states in all technical assistance activities. A focus of **NTAC** is the utilization of all stakeholders to plan, implement, and evaluate these technical assistance activities.

Contact NTAC staff at:
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Fax: (503) 838-8510
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and **Helen Keller National Center**
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Tomorrow's Deaf-Blind Perspectives

Bruce Bull, Managing Editor

"We believe that by presenting the diverse opinions that exist among those who are deaf-blind, their parents, and the professionals who are involved with them, we shall begin to accept the differences that exist within the field and perhaps reconcile some of those differences. Thereby, we might help to build a discipline that is united in purpose and yet retains its diversity."

Bud Fredericks, 1993

This issue marks the beginning our fourth year of *Deaf-Blind Perspectives* (*DBP*). With the recent funding of National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) and refunding of DB-LINK—two of three sources funding this publication—the time seems right to examine how we can best achieve our above-stated purpose. Additionally, I have included findings from the recent *DBP* readership survey that has provided, and will continue to provide, direction to *DBP*.

DBP could not exist without the support of two national deaf-blind projects: NTAC and DB-LINK. Though one function of *DBP* is the dissemination of information pertinent to these projects, we have also make every effort to be more than just another project newsletter. One expected result of combining the national deaf-blind technical assistance efforts of TRACES and HKNC-TAC into NTAC is that *DBP* will reflect the collaboration within this project. Because one of NTAC's charges is to improve services to individuals who are deaf-blind, birth to age 28, *Deaf-Blind Perspectives* will increase its solicitation of manuscripts that focus on young adult issues.

DB-LINK too has an expanded work focus that will affect *DBP*. The DB-LINK Research-to-Practice Initiative (see article on page 1) will work toward dissemination of information related to effective practices—whether developed in research projects, 307.11 projects, or elsewhere—to families and professionals. DB-LINK will facilitate the transfer of helpful information to those who can make a difference in the lives of people who are deaf-blind. *DBP* will be method for disseminating these effective practices.

DB-LINK and NTAC naturally flavor *DBP*. But the readership too shapes the publication through both its contributions and feedback. In the Winter 95/96 , (Vol. 3, Issue 2), we included a readership survey to solicit reader feedback. A non-representative group of respondents, just over 3% (n = 80) of the readership, took the time to provide input. We appreciate it; and we've listened. I've highlighted just a few of the findings here and the direction that this input will provide. (Complete survey results are available upon request.)

Survey Results

Nearly 78% of respondents felt that *DBP* was "very important" in keeping them informed about the field, and 57% of them read each issue of *DBP* cover-to-cover. This group most frequently listed *DBP* as their main source of information about deaf-blindness. To this small respondent group, *DBP* plays an important information dissemination role. That is why we've listened and responded to their suggestions.

- Two-thirds of those who answered the question about whether we should add a "Letters to the Editor" feature responded positively. We've taken that suggestion beginning this issue. Obviously, this section is dependent on readership participation. We look forward to your opinions.
- Respondents favored "how-to articles" more than any other type. We actively seek out content and how-to articles. One difficulty is that many potential contributors who may have valuable information to share may not have the time to write. I ask you be creative, find someone who would be willing to collaborate with you on the writing task. If you're in a classroom, have a practicum student work on a piece with you; if you're in a parent

group, write something with other parents; if you're at a college, collaborate with a graduate student. I know that many of you have information that others can use to improve the lives of people who are deaf-blind. Please share it with us.

- "Advocacy and policy updates" were favored second. *DBP* will continue to keep the field updated, especially during this crucial period while IDEA is up for reauthorization.
- "Research descriptions/quantitative pieces" were favored third. The DB-LINK Research-to-Practice initiative will feed some of the demand for this information, but we will continue to seek out projects in order to utilize *DBP* as a vehicle for dissemination of project findings.
- "Calendar of event" pieces were least favored. We won't include such information unless it specifically targets the field, covers a wide geographical area, or there is substantial lead time before the event. Our publication frequency does not allow us to serve adequately as a provider of more general and/or local information.
- Finally, over one-third of the respondents indicated they would be interested in writing articles for DBP! This is encouraging. By "presenting diverse opinions," we can indeed "begin to accept the differences that exist within the field and perhaps reconcile some of those differences."

DBP has been, and will continue to be, open to everyone—parents, professionals, people who are deaf-blind, and researchers—to contribute to the publication. Amalgamating the best of what the entire field has to offer and sharing it with our ever-expanding readership (currently 2800+) is what *Deaf-Blind Perspectives* is all about. Help us to achieve our purpose.

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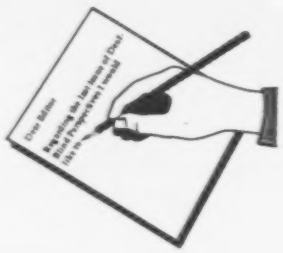
Want to share your opinion? Take a few minutes to write a Letter to the Editor. Please keep letters to 250 words or less. The editorship is developing a policy for this section.



Letters to the Editor

Dear Editor:

I appreciated Bud Frederick's article, "Reflections, Comments, and Suggestions" (Spring 1996), drawing attention to the role of family services. I hope that 307.11 projects will truly work to develop better partnerships with families.

When I became a Regional Representative for Helen Keller National Center, there were still regional centers for deaf-blind children in many parts of the country. The South Central Regional Center had a family specialist who conducted workshops and maintained contact with families in the region, increasing their knowledge and sense of self-empowerment. The attitude was that families were the critical political/advocacy component of the service delivery system that ensured services would continue and improve.

In transferring the control of services to a state agency, many educational and advocacy efforts for families were lost. Services to deaf-blind children and to the deaf-blind field as a whole have suffered as a result. This transition has left me with a great sense of loss and uncertainty.

Today, family support seems fragmented. There seems to be less inclination by 307.11 projects to develop real family partnerships. There isn't the same level of commitment to developing friendships with families, to maintaining telephone contact, or to understanding how fundamental the family is to the betterment of programs for deaf-blind children and society as a whole. I don't know how this got lost in the transition from regional centers to state centers, but I wonder if it's not, in part, because the regional centers were more independent and not a part of the bureaucratic state educational system.

C. C. Davis
Regional Representative

Dear Editor:

I concur with Dr. Frederick's recommendation for more parental involvement ("Reflections, Comments, and Suggestions," Spring 1996). However, I also believe we need the involvement of deaf-blind teens and adults of all ages in program development, advisory board membership, and service delivery.

I have been at meetings for parents of deaf-blind children in which no deaf-blind people participated and I have met parents of young Usher adults who have never met a deaf-blind adult!

According to the literature, half of all deaf-blind adults have Usher Syndrome. Parents of Usher kids are not being surveyed about their experiences, which often include early attempts at mainstreaming their children with changes to deaf programs at the request of their children sometime during early adolescence so they can be just like everyone else. In two deaf-blind teens programs, different mothers said to me, "I have never seen my child be so normal before." Both these deaf-blind teen programs had tremendous involvement of deaf-blind adults in planning, counseling, and presenting. This was the first time any of these teens had seen people like themselves in charge.

To omit deaf-blind older teens and adults from planning is to deny that our deaf-blind children can learn anything from people like themselves and; by extension, to imply that our deaf-blind children have nothing to contribute.

Necessary to the success of these programs is the involvement of deaf-blind adults at every opportunity. Parents with newly diagnosed children of all ages can benefit from the wisdom of those who have gone before--other parents and deaf-blind people themselves.

Ilene Miner, CSW, ACSW

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The deaf-blind community lost a very special person in July with the passing of Mary Margaret O'Donnell. Mary's "career" in deaf-blindness spanned more than thirty years during which she was a driving force in the creation of the New Jersey Association for the Deaf-Blind, served on numerous advisory committees at the state and national level, and helped found the National Family Association for Deaf Blind (NFADB). In 1992, Mary was awarded the prestigious Anne Sullivan Medal at the National Conference on Deaf-Blindness, the first parent to receive this award.

At the time of her death, Mary was serving as president of NFADB. A private, understated person who shunned the spotlight and preferred working behind the scenes, she somehow always seemed to end up in a leadership positi[illegible]. For those of lucky to have kn[illegible] personally, it was easy to see why. She possessed a wealth of knowledge but never tried to impress others with it—she simply offered them her support and counsel. She had an inner strength and tenacity that enabled her to stay focused, even in times of great confusion. She was a great listener who was open to differing points of view and never failed to recognize the contributions of others.

Mary was a lovely, thoughtful lady who carried herself with class and dignity in all she did. She will be greatly missed.

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Syndromes, Behavior, and Educational Intervention

J.P.M. van Dijk
Catherine Nelson

Introduction

In the past decade, clinician interest in syndromes has increased tremendously. Recently Gorlin, Toriello and Cohen (1995) published a book in which 400 hereditary syndromes associated with hearing loss are described and several of the descriptions make reference to the behavior of the individual with a particular syndrome.

The relationship between heredity and behavior was noted in 1872 by Charles Darwin. He wrote

> 'When he lay fast asleep on his back in bed, often raising his right arm slowly in front of his face, up to his forehead and then dropping it with a jerk so that the wrist fell heavily on the bridge of his nose. The trick did not occur every night, but occasionally'

Since the nose of this gentleman became irritated it appeared necessary to remove the buttons of his nightgown. Darwin continues his story as follows.

> 'Many years after his death, his son married a lady who had never heard of the family incident. She, however, observed precisely the same peculiarity in her husband; but his nose, not being particularly prominent, has never suffered from the blow... One of his children, a girl, has inherited the same trick'

(Darwin, 1872, p. 34).

Language expressions such as 'it runs in the family' make reference to the relationship between heredity and behavior. Some researchers and authors have suggested that a person's behavior is solely dependent upon his gene constellation. In reaction to this point of view, behaviorists such as Watson claimed that stimulus-response chains explain human behavior: One of his famous quotes is

> 'Our hereditary structure lies ready to be shaped in a thousand different ways - the same structure - depending on the way in which the child is brought up'

(Watson, 1930)

These points of view lead us to the heart of the discussion of nature (hereditary traits) and nurture (the role of environment and education).

In some hereditary syndromes, nature's role is apparent. A deviant chromosome [15] in Prader-

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Willy Syndrome causes enormous appetite in the children with the syndrome that can easily lead to obesity if unchecked. In Turner Syndrome, one X-chromosome in females lacks a specific trait and it is widely reported that persons with the syndrome have great difficulties in spatial orientation (Schaffer, 1962). However, with this syndrome, as well as others including Usher Syndrome, there is wide diversity in its expression. Rubella is a syndrome not caused by heredity, but rather is acquired in early pregnancy. The extent to which Congenital Rubella Syndrome (CRS) *predicts* a persons behavior, and intellectual and emotional development is largely dependent upon which organs are damaged, and the extent and type of the damage.

It is very important that special educators and others, including parents, understand the influence of certain syndromes on the well being of the individual and his/her family. Cooperation with a geneticist or pediatrician is vital. Bringing typical physical appearance and/or abnormal behavioral patterns to the attention of these professionals may provide crucial leads to the discovery of more about the etiology of the individual. A recent study in the Netherlands (Van Berkum & Haverman, 1995) showed that in a survey of a residential setting for persons with severe intellectual disabilities, 50% of the etiologies were unknown. However, in settings with a strong multidisciplinary focus, the category 'etiology unknown' was significantly less frequently used. The importance to parents of knowing more about the cause of their child's disability should not be underestimated particularly as they make plans to have additional children. Some genetic disorders can be improved through medical interventions that may have a lifelong affect on a person's physical and psychological condition. Recent research has shown that carriers of certain syndromes, while not appearing to actually have the syndrome themselves, may actually have some effects. An example of this is the inborn metabolic disorder called homocystenuria. Without proper vitamin treatment a person who suffers from this disease may deteriorate mentally and physically. Carriers of this recessive

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disease are vulnerable to acquired heart disease that can be prevented by taking a high dosage of Vitamin B6. It is also reported that in another recessive genetic disease, Usher Syndrome, a slight hearing loss might develop in carriers although this finding is not universal (Van Aarem, 1995). Recently we have observed that in non-affected children of a family with members with Usher Syndrome, problems of signal noise ratio were present that made classroom functioning difficult. Since the field of behavioral genetics is so new, it is difficult to say to determine the extent to which certain hereditary diseases explain the behavior and development of affected persons or carriers. However, when interviewing the parents one should pay attention to the presence of [minor] abnormalities in other family members.

There are a number of genetic diseases that involve physical and mental deterioration. Metabolic disorders such as Zellweger and Refsum are notorious for causing such deterioration. Other syndromes have effects that are less noticeable. One example is Stickler Syndrome. A child with this syndrome may function well in school despite a hearing loss, but gradually learning problems arise as visual impairments together with problems with the joints slowly develop.

Recently we have observed that in non-affected children of a family with members with Usher Syndrome, problems of signal noise ratio were present that made classroom functioning difficult.

A syndrome prevalent in the population of persons who are deaf-blind is CHARGE Association. The complexity of the association has increased awareness of the importance of multidisciplinary collaboration. Among the traits of CHARGE Association is hypo-genetalism. When male/female hormones are given to stimulate genital development, behavior such as hypersexuality may result. It goes without saying that all consequences should be considered before medications of this type are prescribed.

The relationship between syndromes, education, developmental psychology and psychiatry has had little study. In clinical, medical descriptions, the effects of disease on behavior and learning is rarely mentioned. The relationship between disease and behavior is not an easy study due to variability of disease expression and the role the environment plays.

Description of three Syndromes

Congenital Rubella Syndrome [CRS]

Congenital Rubella Syndrome is not a genetic syndrome but rather is caused by a virus. In 1941, the Australian ophthalmologist, Sir Norman Gregg, discovered the relationship between Rubella and Congenital Cataracts. He also reported that the babies he investigated had low birth weight and were very difficult to feed (failure to thrive). A few years later, another Australian medical group reported that Rubella infection in pregnancy could lead to partial destruction of the cochlea which caused [partially] deafness. Six years after the discovery by Gregg, the medical journal, 'The Lancet' reported the Australian findings with some hesitancy. In the early and mid sixties, the western world was hit by an epidemic of Rubella that caused almost 35,000 children to be born with one or more sensory disabilities. In 1967, an effective vaccine was developed in the U.S.A. (Parkman, Weller & Neva, 1967). However, it was a number of years before active immunization could be launched. It seems that the most effective policy is to eliminate the disease by vaccinating both male and female children at young age. However, while not common knowledge, there is a small percentage of

women who do not develop antibodies against Rubella and these females remain unprotected. Under supervision of the World Health Organization (WHO), immunization programs are carried out in emerging countries. In some countries with very large populations, the results of immunization programs have been unimpressive thus far. It is reported that in schools for the deaf in India, 40% of the students are deaf/hard of hearing due to Rubella infection of the mother during pregnancy. In some of the eastern European countries, the Rubella problem is still very prominent (e.g., Poland and Russia). It is apparent in discussions with professionals in the area of rehabilitation in these countries, that there is still a lack of knowledge regarding the effects of this disease on the behavior and learning of individuals.

The outbreak of the Rubella epidemic in 1964–1965 provided the impetus for the development of programs for children who are deaf-blind in the U.S.A.. A number of important studies were published which focused on the child with multiple disabilities caused by CRS. Because of the emphasis on the group of children with multiple disabilities, little attention was given to the Rubella child with a single disability (e.g., hearing loss/visual loss). It should be noted, however, that Rubella is a late onset disease. This means that later in life, especially during the period of adolescence, medical problems may arise (e.g., diabetes mellitus and glaucoma) that may have considerable effects on the course of life. There is a general agreement that these problems are most manifest in the group of persons with multiple disabilities.

In the follow-up studies of Chess and Van Dijk, the role played by communication in the regulation of behavior is striking.

An interesting point in the discussion of syndromes and behavior is the relationship between CRS and autism. In her early publication, Stella Chess confirmed this relationship and subsequently, many publications about the etiology of autism mention Rubella (Siegel et al., 1986; Prior, 1987). In his publication in 1982, Van Dijk reported on 81 Australian children with Congenital Rubella Syndrome and questioned this relationship. In reference to stereotypic behavior that is often observed in children with CRS, he postulated that this symptom must not be seen as a symptom of autism but rather as a symptom of sensory deprivation. When Van Dijk reassessed his sample 15 years later, he discovered that in many subjects who had exhibited stereotypic behavior at a young age, the phenomena had disappeared completely. In his follow-up research, only a small group met the criteria for autism of DSM-III (Diagnostic and Statistics Manual of Mental Disorders Vol. 3). Similar findings are reported by Gilberg (1982). In the follow-up studies of Chess and Van Dijk, the role played by communication in the regulation of behavior is striking. It is generally noted that persons infected by Rubella have difficulty in adapting to new situations. Unexpected events cause considerable stress in these persons that may lead to catastrophic reactions. These may take the form of aggressive outbursts in which the aggression may be directed to the person's own body leading to self injurious behavior (SIB). There is question as to the degree to which this behavioral 'trait' is typical for a person with CRS and related to the vulnerable neurological system of these persons. Despite uncertainty as to the cause of the behaviors, it would appear important that people in the environment take appropriate measures to prevent their occurrence. Providing the individuals with an appropriate means of communication (e.g., sign language) may prevent many such behaviors. However, in some instances, sign language because of its motor complexity, is not the most preferred mode of communication. It had been shown (Van Dijk et al., 1991) that

limb coordination can be very difficult for individuals with CRS. To compensate for this difficulty, many individuals have developed strong visual skills. Written forms of communication (e.g., pictograms, BLISS symbols and writing) are more effective communication tools than is sign language. Objects of reference, calendar boxes and picture books can be effective tools for expressive communication for children with greater communication difficulties (see detailed description in Van Dijk, Janssen & Nelson, 1993).

In studying the early development of children who are deaf-blind and particularly those with Congenital Rubella Syndrome, it is apparent how very difficult the early period of life is for both the children and their care givers. This, combined with a rather fragile neurological system, may predict the undesirable behavior patterns of later life. The extent to which this prediction becomes reality is very much dependent upon protective factors from the environment. For these children, adolescents and adults, protective factors are: ordering of daily life activities, predictability, and prevention of unexpected, overwhelming life events. It goes without saying that these requirements cannot always be met. In extreme instances, supportive medication may be necessary to help individuals cope with stressful events.

In studying the early development of children who are deaf-blind and particularly those with Congenital Rubella Syndrome, it is apparent how very difficult the early period of life is for both the children and their care givers.

Usher Syndrome

Mention was made earlier of the heterogeneity of certain syndromes. Usher Syndrome is one in which this is especially true. The Scottish ophthalmologist, Charles Usher, first described this syndrome. In 1935, he lectured on the prevalence of Retinitis Pigmentosa (RP) in a sample of individuals with severe hearing loss. In 1922, Bell noted the heterogeneity of this syndrome, and in 1977, Davenport made a distinction between different types of Usher Syndromes (Davenport & Omenn, 1977). In the last few years, gene localization has clarified the different types (Van Aarem, 1996). Usher type I (profound sensory neuro deafness and decrease in field of vision before puberty) is located on chromosome 11q. Type II (partial deafness and decrease of field of vision after puberty) is located on chromosome 1q. The rather rare type III in which there is progressive hearing loss and progressive loss of field of vision due to RP is located on chromosome 3q. Further gene localization research in relationship to Usher I and Usher II has been conducted by Radboud Hospital (Nijmegen the Netherlands) in cooperation with Boys Town Omaha (Nebraska). It is still unclear whether different gene localization's are responsible for differences in the progression of the disease or even influence the behavior of an individual with the syndrome. In respect to the latter, there has long been discussion about the existence of a fourth form of Usher. Hallgren (1959) reported psychiatric problems, severe stress phenomena and psychosis in a group of individuals with Usher. It is questionable, however, whether this behavior pattern has a hereditary base associated with another type of Usher, or is symptomatic of so-called Post-Traumatic Stress Disorder. This may occur when a person with Usher loses an important person in his/her environment or experiences other traumas such as the loss of employment or becoming unable to care for one's family. Our clinical experience with a large group of individuals with Usher type I is that a 'stress disorder', if it lasts only a short period of time, seldom leads to psychosis if adequate support is provided. Research has been carried out on the psychological resilience of persons with

Usher I. The first author assessed a group of adolescents with a Dutch revision of the American California Child Q-set. People very familiar with the subject's functioning were asked to complete a questionnaire concerning the subject's ego-resilience, ego-strength, social competence, ego-control and self-esteem. The study shows that 88% of the group (N=16) scored high to very high on the profile of ego-resilience in comparison to the deaf children in the norm group. In regards to pro-social competence, it was shown that a significant difference existed when the scores of the Usher group were compared with those of the peers in the norm group. A lack of assertiveness was quite striking. In 89% of the cases of Usher I, there was a high to very high score on the self esteem scale. Because of sample size, caution should be used in the interpretations of the findings. Recently the original sample was reassessed. Four years after the initial research, the same behavioral profile was still found and was also present in 9 additional cases (Van Dijk & Van Erp, in preparation). Our clinical experiences confirm these findings of favorable social emotional profiles in individuals with Usher 1. After having assessed about 100 such individuals (about 1/3 of all individuals with Usher Syndrome in the Netherlands), we have found that they readily accept advice and return regularly to the clinic for counseling. It would be interesting to know whether these striking behavior patterns occur only among the Dutch group or are also found in other samples. One might speculate as to whether this 'emotional strength' is a natural (genetic?) reaction of a human being when experiences such as severe sensory losses occur.

One might speculate as to whether this 'emotional strength' is a natural (genetic?) reaction of a human being when experiences such as severe sensory losses occur.

CHARGE Association

Previously known as CHARGE Syndrome, the term Association was adopted because of the extensive variety of symptoms found. CHARGE association is one of the 25 most prevalent genetic syndromes of individuals with multiple disabilities. It was described for the first time in 1979. Several organs are involved, most of which develop in the 3rd - 7th week of pregnancy. CHARGE is an acronym for its most striking symptoms.

The C is for coloboma. This means that the iris and/or retina is not completely closed leaving an open hole that looks like a keyhole. When the iris is not closed, the light hits the eye in such a direct manner that in clear weather conditions the child is very uncomfortable. Some young children with this condition refuse to go outside when it is sunny. When the retina is not completely closed, the lower part of the retina often does not function. This segment of the retina receives stimuli coming from above. A child with this condition might be afraid of moving targets (e.g. a ball which enters his field of vision from above). The child may only become aware of a person coming down from the stairs when he or she is very near. Fragile health and motor delays common in children with CHARGE may result in the child spending much of his early life lying on his back. When lying down, the lower segment of the retina is normally used, but since this is often where the coloboma is, the child may spend many months in a position where he is severely visually deprived. When the child is put in an upright position and objects are presented from underneath, the exploratory behaviors may dramatically improve. In cases where a coloboma is present, it is likely that the retina is rather weak and it may detach.

This process can develop so gradually that it goes on unnoticed. It is possible that a child with CHARGE Association may gradually become blind without the occurrence of any trauma. Educators should be made aware of the vulnerability of the eyes in children with CHARGE. Observed changes should be reported immediately to an ophthalmologist.

The H of the acronym is for heart abnormalities which are reported in 50% of cases. The A is for atresia of the choanae. The R for physical, and in some cases mental, retardation. The majority of individuals with this Association do appear to have severe cognitive disabilities, however there are cases of individuals with normal intellectual development (Harvey et al. 1990). The letter G represents underdevelopment of the genitalia (both male and female) which is reported in 40% of cases. It is assumed that genital hypoplasia is due to an insufficiency of the hormonal system, therefore some children with the Association exhibit no signs of puberty. As previously mentioned, hormonal treatment should only proceed with great caution. The E is for anything having to do with ears. In 85% cases, hearing loss of varying degrees is reported. When there is an opening of the palate in addition to deafness, speech possibilities are limited. The use of alternative and augmentative communication devises should be considered.

. . .parents also need to be supported as they deal with a child who may exhibit stereotypic or compulsive behaviors.

CHARGE Association is not limited to the 6 symptoms mentioned here. Recently a child was assessed with CHARGE who refused to ride her bike. Further investigation indicated a dysfunction of the vestibular system. She had been so traumatized by attempts to teach her to ride the bike that she would not even go near it, but she immediately went to a tricycle that requires little balance as she knew that she could move independently on it.

Discussion

This article has only touched upon the intriguing question of to what extent certain syndromes are related to an individual's behavior. Behavioral genetics tells us a great deal about the role of the genes and the environment. Studies of twins are very important to the science of behavioral genetics as identical twins have the same genes, yet the environment they share is partially the same (e.g. the same parents) but also different, for example, different friends (Plomin, DeFries & McClearn, 1990). In studies of psychiatric diseases such as schizophrenia and psychoses, it is apparent that whether or not a disease that is 'in the genes' manifests itself is dependent upon the non-shared environment. Important environmental factors mentioned are stress, early deprivation, limited, or poor social contact with parents, and divorce (Plomin & Daniels, 1987). In behavioral genetics, emphasis is placed on supporting the factors that may prevent a person with a certain predisposition from developing difficulties. Family relationships, especially mutual support of the parents (see also Van Dijk, 1991), adequate counseling, and a thorough diagnosis are such supports.

It is our opinion that findings of the behavioral genetics also apply to children who are deafblind. We would like to stress the importance of the manner in which people in the environment deal with a child with CRS, a child with Usher Syndrome, or a child with CHARGE Association. For a child with Congenital Rubella Syndrome, parents and other caregivers need to support the child through the organization of a quiet and understandable world. At the same time, parents also need to be supported as they deal with a child who may exhibit stereotypic or compulsive behaviors.

Good respite care by trained providers such as intervenors can provide such support.

Parents and siblings of a child with Usher Syndrome may go through an extended period of mourning which can prevent the child from developing to his/her fullest potential. The family may avoid the whole topic of the child's eyes. Teachers or employers may not even be told about the child's condition. Counseling which takes into account the family system should be considered. The goal is to create a climate in which the child with Usher Syndrome can make important decisions in his/her life.

There are many obstacles that the family of the child with CHARGE Association must deal with. In the beginning, medical issues may be overwhelming and extremely stressful. Parents will need good information on how the child should be fed and how hearing aids and glasses should be worn and used as they learn that they can help their child learn and develop in positive ways.

The field of genetics a rapidly growing one. There are more than 400 syndromes described in which deafness plays a role (Gorlin et al., 1995). In about 20% of these syndromes, both auditory and ocular involvement are reported. It is our sincere belief that only through the various disciplines working together as a team can adequate care for the child and his/her family be provided. Decisions by the team should always include the parents and if possible, the individual with the disability. The team must formulate recommendations that carefully consider the role of the environment. It is our conviction that negative outcomes can be prevented despite the presence of many symptoms. We have adapted a motto that the more one knows about 'genetics' the more one becomes aware of the importance of the role of the environment.

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We encourage you to copy and share information from *Deaf-Blind Perspectives*, but please provide appropriate citations.

Words From the Past Managing Editor

Bruce Bull

Given a point-in-time perspective, things seem static. Over time however, it is apparent that everything is in a state of change; our jobs, our world, and ourselves. Little did I know that the previous issue of *Deaf-Blind Perspectives* would be my last. I have recently taken an exciting position within the Oregon Department of Education and wanted to share a few parting thoughts.

Deaf-Blind Perspectives too is poised for change. In the last issue we started a Letters to the Editor section, an important forum for people to share, discuss, and challenge. Keep the letters coming! Keep the publication alive with dialogue about the issues.

During my tenure at *Deaf-Blind Perspectives* we would always seek quality manuscripts. The focus of each issue changed based on the contents. The better the content to choose from, the better the publication. Let me encourage you to submit manuscripts of a personal or professional nature. If you'd like to see change in some aspect of our field, use *Deaf-Blind Perspectives*.

About change, my father used to say, "A change doesn't always bring improvement. But you can't improve without change." Let's continue to work to improve this field.

We will miss you Bruce, and wish you the very best.—ED.

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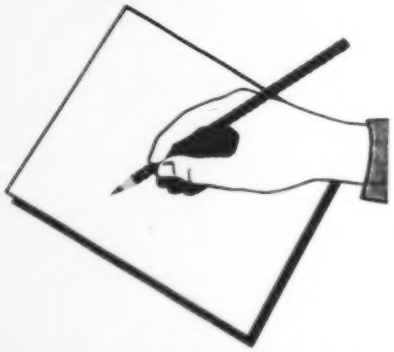

Letters to the Editor

Dear Editor,

Over the course of the last few years a number of agencies and associations in the field of deafblindness have dropped the hyphen from the disability category "deaf-blind." It is our opinion and suggestion that *Deaf-Blind Perspectives*, a distinguished publication both nationally and internationally in this field, adopt this current terminology.

There are good reasons to consider this change. First, deafblindness presents challenges that are not simply the compilation of deafness and blindness. In 1991 Salvatore Lagati wrote to 30 agencies around the globe stating:

> I think that people that are deaf and blind should be called deafblind, and not deaf-blind. For the simple reason that deafblindness is a condition presenting other difficulties than those caused by deafness and blindness. So in my mind the word deaf-blind is not correct, because it could be interpreted as a condition that sums up just the difficulties of deafness and blindness.

Second, many, if not most, countries now refer to the disability as a single word without the hyphen. Moreover, increasingly agencies within our own country are changing to this terminology (e.g., Hilton/Perkins).

Please consider using the term "deafblind" both in the title of your publication and throughout your publication. *Deaf-Blind Perspectives* serves as an important medium through which professionals, families, caregivers, and people who are deafblind access state-of-the-art information relative to our unique field, and we encourage you to promote this change to better support a more accurate understanding of deafblindness.

Sincerely,

Bruce Bull
Special Education Child Count Specialist
Oregon Department of Education

Bud Fredericks
Professor Emeritus
Teaching Research
Western Oregon State College

Jay Gense
Coordinator
Oregon Project for Deafblind Services
Oregon Department of Education

Steve Johnson
Associate Superintendent
Office of Special Education
Oregon Department of Education

Jane Mulholland
Assistant Superintendent for Special Schools,
Regional Programs and Early Intervention/Early
Childhood Education
Oregon Department of Education

Deaf-Blind Perspectives, recognizes the diversity in opinion regarding this issue and does not wish to make changes hastily. We therefore invite you to comment with Letters to the Editor.

To assist us in making an informed decision about any modification of the term "deaf-blind," *Deaf-Blind Perspectives* particularly invites the views of people who are deaf-blind, their families, and the professionals who serve them.

We will attempt to print a representative cross-section of your views in subsequent issues. —ED.

Want to share your opinion? Take a few minutes to write a Letter to the Editor. Please keep letters to 250 words or less.

The Hilton/Perkins Program Announces-

1997 National Conference on Deafblindness

The Individual in a Changing Society
June 6-9, 1997
Washington Hilton and Towers
Washington, D.C.

This conference will focus on the needs and rights of people who are deafblind and how these needs and rights will be affected by a changing society. The conference will address a wide array of issues confronting infants, school-age children, and adults who are deafblind, their families and the professionals who serve them.

For more information, contact

The Hilton/Perkins Program
175 North Beacon Street
Watertown, MA 02172
Ph. 617.972.7228
Fax 617.923.8076

No registrations will be accepted after May 31.
No on-site registrations will be permitted.
Late registration fees apply after April 6.

Deaf-Blind Perspectives

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Deaf-Blind Perspectives

Volume 4, Issue 3 Spring 1997

Issues and Concerns Related to Inclusive Education for Students Who Are Deaf-Blind

Findings of the Task Force of a Model Demonstration Project

Terry Rafalowski Welch
Webster, New York

Lori Goetz
San Francisco State University

A national task force of individuals involved in a variety of settings with students who are deaf-blind was created as part of a model demonstration project. Its purpose was to examine inclusive educational practices for students who are deaf-blind. The project, Full Inclusion Programs for Students Who Are Deaf-Blind Model Demonstration Project (OSERS Grant #H025D30013, Lori Goetz, Principal Investigator) combined input from project personnel working at sites in California that serve students in inclusive programs who are deaf-blind, with that of the task force. This article presents the activities, responsibilities, and findings of the task force. In particular, it focuses on issues specific to programs serving students who are deaf-blind.

Background and Special Features of the Task Force

The task force was composed of 13 members, in addition to project staff: Two parents of deaf-blind students, three directors of national research projects, four directors of 307.11 projects (including state projects), two representatives of national technical assistance projects for programs serving individuals who are deaf-blind, one consultant in deaf-blindness, and one representative from an institution of higher education. The roles of some task force members overlapped several of these categories. Its members met twice annually since 1994, gathering each time in San Francisco with key project staff.

Most often, the national components of a demonstration project are either programs included in the project's network of sites, or the representation from the project's advisory committee. The work of this task force differed from these two entities in that it was broader than that of a particular demonstration site, and it included more direct involvement than an advisory committee. The Full Inclusion Project's proposal delineated the charge of its task force as "to address the inclusion of deaf-blind students in fully inclusive programs... to pursue specific content problem areas and potential solutions, as well as to analyze effective practices." (Goetz, 1993, p. 11). The design of the proposal specifically focused the work of the task force on addressing, from a national perspective, the barriers to successful inclusive programs for students who are deaf-blind.

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From the first meeting it was evident that task force members and project personnel were committed to and energized by working together. The group's first order of business was explicitly defining inclusive programs (cf. Sailor, 1991). The Project's proposal specified programs in which students who are deaf-blind "are full-time members of age-appropriate, regular classrooms in their home schools, and receive any supports necessary to accomplish participation in both the learning and social communities of their peers." As case studies unfolded, however, it became evident that not all case study situations reflected full inclusion defined in this way. For example, not all students were served at their home schools and not all students were

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exclusively members of general education classes. More implicit, but very strongly held by task force members and project personnel, was the understanding that "successful" inclusive programs for students who are deaf-blind ensured that they are "...not only served, but well-served, in programs which protect their unique service needs while supporting full membership in the life of the school" (Goetz, 1993, p 4). Accomplishments of full inclusion programs would be considered in relation to these dual outcomes of academic achievement and social participation for students who are deaf-blind.

The task force was fortunate to include among its members three directors of current research and demonstration projects on the study and support of social relationships of individuals who are deaf-blind. At some of the earliest task force meetings, these three directors shared insights and initial findings of their own project work (R. Horner, Research on Social Relationships for Children and Youth with Deaf-Blindness, #HO25R20002; H. Mar, Social Relationships of Children and Adolescents with Deaf-Blindness, HO#25R20004; N. Haring/L. Romer, Lifestyle Planning and Enhancement Project, HO#25D30001). Each emphasized different and essential dimensions of relationships and their development: reciprocity, creating social opportunities, and peer training (including both the training of student peers and the use of adults who are deaf-blind as "peer" instructors). These presentations added depth and breadth for further understanding a target outcome of social participation.

Work of the Task Force

From the start, task force members agreed that case study presentations were to be central to their meetings. The studies would form the basis of group discussions of issues and concerns related to

Research to Practice
A Focus on Inclusion

Parents and teachers of children and adolescents who are deaf-blind frequently have questions about inclusive education programs. Several typical questions were presented to Dr. Lori Goetz , director of the recently completed project, ***Full Inclusion Program for Students with Deaf-Blindness.***

(Q) As a parent of a school-age child who is deaf-blind, I have fought for years to get the special services and programs my child now receives, like an intervenor, a teacher who can sign, a vision consultant, and special equipment. Would my child lose these services if she attends a regular class in the public school?

The answer is NO. Placement in a regular class does not, and SHOULD not, mean a loss of services. Our experience has shown us that when an effective and collaborative teaming process is in place for all of the specialized service providers, and

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inclusion, and documentation of the studies would be ultimately the foundation of several of the final products. Together, project staff and task force members outlined several key points to guide the development of the case studies. This group also shared tasks of designing and refining questionnaires to collect information about the following topics: (a) the related services available to students (e.g. interpreters, O&M services); (b) the presence of inclusion indicators reflecting best practice; (c) student characteristics; (d) site demographics; and (e) family history related to inclusion. Each of these questionnaires was completed by a team that included the student's parent, inclusion support teacher, and task force member. This data was analyzed to provide a data-based "snapshot" of the students, school programs, and families who participated in the case studies. It is discussed in detail in a separate document (Solo, 1996).

Project staff and task force members established a schedule for the presentation of individual case studies with each task force meeting including two or three reports. As planned, the presentations provided the forum for the task force to carry out its charge. Discussions held an important added benefit, serving as a kind of technical assistance consultation for specific students. The exchanges of the group sometimes became informal problem-solving sessions addressing difficulties students and/or their families and/or their instructors were experiencing. The project staff and task force members could carry back to students' teams the suggestions and possible solutions generated by this rather uniquely qualified group.

Issues

A number of issues emerged from the evaluation of case study reports, some common to inclusive programs in general and others specific to those serving students who are deaf-blind. Issues frequently encountered in the development of inclusive programs in general involved the following:

- The need for a primary support teacher (i.e., someone who takes the lead in the inclusion process for an individual student (Stainback & Stainback, 1990a).
- The need for ongoing, broad-based training of program staff and students on strategies to facilitate effective inclusion of the focus student (Stainback, Stainback, & Forest, 1989).
- The need for integrated services (Rainforth, York, & Macdonald, 1992).
- The need for parental involvement (Strully, Buswell, New, Strully, & Schaffner, 1992), and
- The need to develop students' sense of belonging in their school communities (Stainback & Stainback, 1990b).

Several of the above issues appear to be amplified by the complexities of deaf-blindness (cf. Haring & Romer, 1995).

The case studies also identified issues not ordinarily cited as obstacles to inclusive programs. Since these issues may be of special interest to educators in the field of deaf-blindness, details follow.

when there is an inclusion support teacher to coordinate and integrate specialized services with the regular education curriculum, students don't lose any of the services or equipment that they and their families have fought for, and the learning outcomes for these students are just as good as (if not better) than learning that happens in more self-contained settings.

(Q) Are some children who are deaf-blind more likely to succeed than others in an inclusive education program?

Our project has had experience with all different ages and ability levels that are represented in the "deaf-blind" population. We've worked with a preschooler who has multiple support needs in terms of motor, cognitive, and communicative functioning, and a junior high school student who participates at grade level in the core curriculum. I don't think it's a matter of the "type" of student, but instead it's a matter of having the necessary supports and services integrated into the regular education program.

(Q) What resources (e.g., videotapes, articles) do you recommend that would help parents and teachers learn more about inclusive schooling?

I would suggest contacting DB-LINK, The National Information Clearinghouse On Children Who Are Deaf-Blind. Ph. 800-438-9376, TTY 800-854-7013.

(Q) I'm a math teacher in a junior high school. Next semester, I will have a 13 year old student who is deaf-blind and cognitively disabled in one of my classes. I need help, but where do I start? How do I make abstract math concepts meaningful for the student? How can I attend to this one student when I have a class of 24 teenagers?

Curriculum adaptations are essential here. It may be a matter of pro-

The Need for Additional Instructional Time

The most basic guidelines for the instruction of students who are deaf-blind emphasize the importance of allowing for added time (Gee, 1994; Welch & Cloninger, 1995). An exchange of information involving an individual who is deaf-blind simply takes more time. Several of the case studies underscored this point. This need existed both during school hours and after.

Several studies reported that academically capable students who are deaf-blind faced a variety of obstacles related to school work. As students progressed to middle school and high school levels, in particular, it was increasingly difficult for them to keep abreast of the volume and pace of academic content. When students who are deaf-blind chose to follow the standard general education curriculum and ultimately earn a general education diploma, rather than pursue an altered curriculum and a special education diploma, the options for lessening workloads narrowed.

Reports noted that keeping up academically with peers can place added stress on a student who is deaf-blind. Students who are deaf-blind expend considerable effort in classes to receive and interpret auditory and /or visual information. This is very fatiguing for students (Prickett, 1995). There were also numerous descriptions of conditions which could contribute to sensory overload for students who are deaf-blind, such as the complex sensory demands of routine transitions between high school classes which are simply taken for granted by students who are not disabled.

Many of the options available to keep up academically with peers were unappealing to students or conflicted with some of the desired social benefits of inclusion. The options included (a) eliminating elective subjects that might be of special interest to a student in order to allow for additional study time; (b) increasing "pull out" time for tutoring and concentrated study; and (c) extending the school year through the summer months. Such "solutions" essentially risked isolating or segregating a student. Several graduation alternatives included extending high school education through age 21 (although the student would not graduate with peers) and leaving high school without a diploma to complete a GED later. Again, these alternatives presented significant disadvantages and conflicted with general goals.

Several case studies noted homework in relation to the issue of added time. As would be expected, the hours involved in the completion of homework expanded also, due to the complexities deaf-blindness presents for receiving and conveying information. Added to this is the expansion of the volume of homework as a student's grade level increases. Accounts of students who are academically at grade level and who are also deaf-blind detailed the stress the students and their parents experienced with students' homework assignments. The students, already fatigued by their need to focus attention and concentrate during the school day, were finding the extension of such efforts exhausting. Some parents felt compelled to take on a role of teacher or tutor for their children at home; one case reported that parents were essentially re-teaching material at home. In addition, the pace of classes was such that the student missed important information, even with the advantage of a skilled interpreter.

viding the written lesson information in braille. It may be a matter of deciding that while the student who is deaf-blind will not master algebra rules, he may participate meaningfully in other ways, such as through distributing materials to each class member throughout the lesson. Or, your student might have a rotating peer partner to help him complete modified activities, such as tactile scanning to compare lengths, that have been specifically prepared by an inclusion support teacher who knows the student and his IEP goals and objectives.

(Q) How do you get other kids to communicate and interact with the student who is deaf-blind in an inclusive school? What are some of the more effective strategies to promote social relationships?

There are lots of strategies a team can use. Our research and has found three things that are really helpful.

1. Providing information about the student through class activities like signing clubs, circles of friends, and ability awareness lessons.

2. Providing interactive communication media through computer adaptations, games, and media that support kids in interacting with each other.

3. Teacher facilitation through jumping into a shared activity when help is needed, and then backing off to let students interact directly with each other to solve a problem or to have fun.

(Q) If I am interested in having my child in a full inclusion program, who should I talk to and what are some of the first steps I might take?

I think it's always a good strategy to be networked with other parents who have their children in inclusive programs, especially at the local level. Visiting these programs in your own district is one way to get information about what is possible and working. Other resources in-

Technological supports did not seem to eliminate the complications of or overcome the challenges of information exchange for students who are deaf-blind. In fact, task force members noted have instruction in the use of alternate media and devices made further demands on students' class time.

Use of Interpreter-Tutors or Intervenors

Discussions of the use of and/or need for interpreter-tutor or intervenor services by students who are deaf-blind were common to many of the case studies. This was not surprising, as this is frequently a key topic in education of individuals who are deaf-blind, regardless of students' placements (Ford & Fredericks, 1995). Studies echoed current concerns of the field, particularly the lack of definitive job descriptions and job qualifications for roles that extended beyond that of a certified interpreter. Reports exemplified the inconsistencies that exist from state to state and even, in some cases, from district to district within the same state. Other concerns included finding individuals to fill such positions, the types and amount of assistance that these individuals should provide students, and rapid turnover of staff which was disruptive to a student's program.

Discussions of the task force focused on the balance of appropriate responsibilities for both teachers and interpreter-tutors or intervenors. In inclusive settings the position of interpreter-tutor or intervenor held added importance and presented additional challenges when the individual was a student's key communication partner in the school program. The relationship between the interpreter-tutor or intervenor and the student, as well as the student's family, in some cases surpassed a working relationship. The roles of teachers, interpreter-tutor or intervenor, and advocates are easily blurred.

Developing Social Supports and Friendships

The case study reports, as well as reports from the research projects, addressed the issues of students who are deaf-blind truly belonging within their school communities, building social relationships and networks through school activities, and fostering friendships through school. Some reports noted the establishment of peer-based social support networks in individual schools. At several sites, regular meetings of "peer buddies" (Alwell & Gee, 1994) were organized to provide opportunities for students who are deaf-blind to meet other students and develop friends. Groups at some sites focused on sensitizing and familiarizing peers with aspects of deaf-blindness. They also presented strategies for bringing about direct interactions with students who are deaf-blind. Group discussions sometimes evolved to address concerns of students in general, but still considered the added impact of deaf-blindness.

Other groups focused on activities that attracted students simply because the activities themselves were fun or appealing. Also, the activities selected were purposefully accessible, recurring, and those which the individual enjoyed (cf. R. Horner, 1996). Frequently, personnel from special research, demonstration, or system change projects initiated the development of the various peer groups within schools.

Several case study reports noted that specific schools had adopted the general philosophy, "All students belong." At such sites, the develop-

clude a state TASH (The Association for Persons with Severe Handicaps) chapter, or your state 307.11 (Deaf Blind Services) project in order to put you in touch with a network of successful parents and teachers who are implementing, or trying to implement, inclusive education.

(Q) What other materials or resources will your project have available for teachers and parents?

We have a couple of manuals that I think could be very helpful:

1. *Inclusive Instructional Design: Facilitating Informed And Active Learning For Individuals Who Are Deaf-Blind in Inclusive Schools*, by Kathy Gee, Morgen Alwell, Nan Graham, and Lori Goetz (1994). This manual reflects six years of project activity focusing on including students who are deaf-blind. It can be ordered through the California Research Institute at San Francisco State University, 612 Font Blvd., San Francisco, CA 94132. Cost: $15.00.

2. As of June, 1997, we will also have a manual of case studies available that tells the stories of a range of students who are deaf-blind as they've become general class members. It is titled *Including Deafblind Students: Report from a National Task Force*, L. Goetz, Editor. The cost is to be determined; it will also be available from the California Research Institute at the address listed above.

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ment of social networks for students who are deaf-blind appeared to be easier, since involvement and participation in school activities were basic expectations.

Fundamental to belonging is mutual respect. Case study reports provided accounts of how the efforts, talents, and needs of students who are deaf-blind were respected by their peers. One report described how a student who is deaf-blind, though very social and active in his class activities, would usually eat by himself, seated away from others in the school cafeteria. Initially, his educational team, consultants, and concerned peers wanted to "problem solve" this situation in which the student seemed excluded. Later discussions recognized that the student chose to eat alone; his preference based, perhaps, on a desire or need to take a break from the efforts involved in the exchange of information—a simple desire not to converse. Task force members, in their own discussion, speculated that the environment also may have contained too much ambient noise or other distractions for easy communication. Most important, whatever the reason, the student's individual choice was respected.

Reports from the social relationships research projects directed task force discussions to the reciprocal nature of true friendships. Several accounts of personal observations of interactions between general education students and those who are deaf-blind, and both formal and informal interviews or discussions with regular education students, affirmed this "dimension" of their relationships. Some regular education students felt they shared a friendship with their peer who is deaf-blind, and received at least as much as they contributed to the relationship.

Communication

As one would expect in almost any project involving students who are deaf-blind, communication issues and concerns were woven throughout the case study reports and research work. Reports indicated that several students primarily utilized interpreters, interpreter-tutors, or intervenors for most communication needs. While recognizing that the provision and easy access to such services were vital for students who are deaf-blind, task force members expressed concern that, if the support person were a student's only direct communication partner, an inclusive setting could still be very isolating. task force members seemed to agree that communication support personnel in school programs had dual key functions: the clear provision of information and the facilitation of direct communication with instructors and peers. Case study reports described a variety of other strategies employed, where appropriate, to support more direct communication, including (a) on-site sign language instruction for staff members and students, (b) use of FM systems and other amplification devices, (c) informal instructions in the use of individual communication systems and devices, and (d) awareness activities related to deaf-blindness and nonsymbolic communication modes.

The concerns of the task force members for the communication needs of students who are deaf-blind extended beyond the basic necessity of supporting direct communication partners. In the project's Inclusion Indicators Questionnaire, task force members were directed to collect information on whether a *"student receives planned assistance to facilitate social network building with peers who provide a linguistic community."* This item reflected the task force's recognition of students' needs for natural language models and access to deaf-blind culture.

Summary

The case study reports by task force members have provided a series of "snapshots" of how programs throughout the country have approached and addressed inclusion of students who are deaf-blind from the varying perspectives of the different individuals who authored these case study reports. The salient issues and barriers discussed here, and their potential solutions, are offered in the hope that when all the reports are synthesized and made available through the project manual (Goetz, 1997), readers will feel supported in their own efforts to include students who are deaf-blind in regular education programs. In addition it is hoped that they will glean strategies that will directly benefit their students.

Author Notes

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Terry Rafalowski Welch is a consultant in deaf-blindness in New York State and was a contributing author to and an editor of Hand in hand: Essentials of communication and orientation and mobility for your students who are deaf-blind, a publication of the American Foundation of the Blind Press, New York, NY.

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THE LONGEST DAY OF THE YEAR

Lisa Manfuso

For as long as I can remember my father talked of retiring. He even had the days, hours, and finally minutes timed for the last five years of his "career" on an assembly line at General Motors. He would get up every morning, look himself in the mirror, and tick another day off the old calendar he kept in the bathroom. He was 52 years old when he retired. A very active, young, athletic, 52-year old man The jubilation of retiring, with no specific time to get up, no lunch to be made for work, no workmates, eventually got the better of him. He began to putter with his cars, and with his boat. My dad owns a 22' day sailor that he uses out on the Chesapeake Bay. He learned how

to sail recently, in the last ten years, navigating his small boat on the sometimes choppy Chesapeake.

The morning of June 20th dawned early. I awoke to the keening of my deaf/blind son Mark. We started our days early, waking before the sun. The earliness never bothered me and I enjoyed the quiet of the morning with Mark. He had just finished school, and was enjoying some time off between school and the beginning of summer school. I noticed that the calendar indicated that this morning was the first day of summer. Judging by the weather forecast, I would say that summer had arrived on time. The forecast was to be sunny, hot and humid, as Maryland summers are infamous for. I thought of taking the kids to the pool, then the phone rang. It was my father.

There is something that I must interject before we go any further with this story. You see, my father was uncomfortable taking the children out on his boat. He was afraid that they would fall overboard, or something like that, and that somehow he would be responsible. Especially for a child like Mark, who had no sense of fear of the water, and when put in unfamiliar surroundings became quite upset. We spoke about the first day of summer, and Dad reminded me that it was also the longest day of the year. I asked him what he was going to do with his day, and he gave the same answer as he had all week,"Putter with the boat." I grinned, the mental image of my father at the marina, working on his already meticulous boat. "Want a crew?", I asked, imagining the wind in my face. Expecting him to balk or say no, surprisingly he said,"Sure, when can you be ready?"

As I got Mark and his younger sister Kristen ready to go for a day cruise, I became apprehensive. We had never done this before. Kristen understood the rules of the boat since she had spent a whole week out on this small boat with her grandparents, but Mark? How was I to handle him? Would he even keep a life jacket on? Would he become upset, and overwhelmed at the sensation? As apprehensive as I was, I am definitely sure that my father was more so. He had seen Mark keening, and overstimulated. At that time, Mark was head-to-head with me, and physically just as strong. I became very nervous as we arrived at the marina. As we approached the boat, Mark tried to walk off the pier, unknowingly of course, but scary enough to keep my nerves on edge. He was not on familiar ground, and made his body very stiff, and almost unmovable. It took both my father and I to maneuver him into the boat and down below to the cabin. I put his life vest on, he took it off. I put it back on, he took it back off. Dad was above trying to hoist off from the pier, and needed my help. Kristen clamoring for attention was singing a song, trying to amuse the anxious adults.

Motoring out away from the docks, I saw the worried expression on my father's face as Mark's keening increased. In the middle of the channel he set sail, and the wind kicked up the sails. Soon after, the gentle rocking of the boat seemed to relax Mark, and the soulful keening stopped. He was sitting on the bottom of the boat, between the kitchen table and the sofa in the small cabin. The faster the boat sailed, the more relaxed he became, allowing me to put his life vest on. Soon, the wind picked up and we heard giggling coming from the cabin at the sensation of the boat careening through the water, as if it were made of paper.

After a half an hour passed, my father and I relaxed. Out in the bay, we felt the wind kiss our cheeks. The white puffy clouds hanging like cotton in the sapphire sky. The salt water spray splashed at our cheeks softly. The smell of the sun, and the canvas sails, and the bay air all mixed together for a soothing but exhilarating tonic. Mark was giggling so hard down below that he was rolling on the floor. My father and I looked at my children, his grandchildren in wonder. After, a short while, I wanted Mark up in the cockpit with us, so he could also enjoy the air. As I pulled him, up I noticed Dad becoming anxious again, but he said nothing, as he assisted in retrieving the giggling Mark.

Sitting in the cockpit, at first Mark stopped giggling. He had also stopped laughing, looking as apprehensive as I felt. The wind died down, and the boat came to a halt. Mark, began to vocalize his anxiousness. The wind puffed gently at the sails, and we were off once again. Mark's face split into a big grin The wind picked up whipping into our faces with a frenzy. The sails puffed and strained with the exertion of the tension. The mast groaned as we picked up speed. I was helping to trim the sails, Mark sitting close to me giggling and tightening his body with excitement. He seemed to say with his body "FASTER, FASTER," laughing as we went. The day progressed and we sailed for hours. We set sail for a small island where my father set anchor and we started to have lunch. Mark wanted no part of it. He kept moving his body, taking my hand and pulling me, as if he wanted to go. Not communicating with tactile signing or fingerspelling, we determined that he was not yet finished sailing, and was becoming increasingly frustrated. In a good humor, my father picked him up and threw him into the Bay. He quieted down quickly, laughing, as swimming is his favorite activity in the world. Soon, we all joined him, laughing at the marvelousness of the day, and the treasure that Mark had bestowed upon us. Sailing back to the marina was a quieter sail, for it was late in the afternoon and the wind had died. It was fortunate for us that the gentle breezes and lulling rocking of the boat, the summer

warm sun, and a full belly made Mark very sleepy. He relaxed and sighed contentedly, making my father comment that he also would like to take a nap.

We pulled up to the docks, Mark and Kristen both asleep down below. My father quietly trimming the sails so that we could maneuver in to his slip at the marina. It had been a wonderful day, one that none of us will forget. Mark likes to sail now. Always anxious at first, until he remembers his friends; the wind, water, and of course --the sails.

(This story was written two years ago. Mark is now 15 years old, has become a great companion on the boat, and still finds his friends the wind, and water. My father still has the boat, and is still retired.)

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Usher Syndrome Family Weekend

Madeline W. Appell, Paul M. Molloy, Ilene Miner, and Jerry Petroff

A family weekend conference for children and youth in New York and New Jersey who have Usher Syndrome was held February 14-17 at the Woodcliff Lake Hilton in Woodcliff Lake, New Jersey. Forty children, teenagers and young adults came with their families for a series of lectures, seminars, and discussions about the challenges of progressive dual sensory impairment. Professionals from a variety of disciplines and adults with Usher Syndrome were also invited. A number of young adults with Usher Syndrome who attend college or are employed came to share their experiences with the younger participants and serve as lecturers, role models, and confidants.

Sessions were held on a variety of topics, facilitated by individuals with expertise in each field. Highlights from some of these sessions are listed below.

Communication and Information

Mary Ann O'Neil, and John Reiman, Ph.D.

A major goal of this conference was to help parents establish communication with their children, other parents, and professionals and to give them an opportunity to meet and talk with adults with Usher Syndrome. Formal communication sessions, facilitated by Mary Ann O'Neil, provided a forum for parents and professionals to discuss communication barriers and for parents to begin plans to network with one another. Informal discussions continued long after the formal sessions, and plans for continued networking had been initiated by the end of the weekend. Participants also learned how to find information to learn more about Usher Syndrome and issues related to deaf-blindness.

Medical Issues

Sandra Davenport, M.D. and John Mascia

The complex genetics of Usher Syndrome were explained with the use of remarkable models created by Dr. Sandra Davenport. Families and individuals with Usher Syndrome could visualize inheritance patterns by handling models of chromosomes, genes, and DNA, the building blocks of inheritance. Dr. Davenport also simulated the visual field and hearing loss of each child and youth for family members by using special eyeglasses and plugs to block hearing. John Mascia talked about cochlear implants.

Orientation and Mobility

Joe Cioffi

Participants openly shared their feelings and experiences about using a cane and about their mobility instructors and teachers. Many of the feelings were negative, but some participants shared positive experiences. Two teenagers stated that their self-esteem had increased since they started using canes because they are now able to protect themselves and maintain their independence.

Access to Services

A. Landi, I. Popkin, D. Steele, and P. Lago-Avery

A panel comprised of individuals representing state agencies that provide rehabilitation training for individuals who are deaf-blind described how to access services. In addition, a representative from the National Technical Institute for the Deaf, Patty Lago-Avery, who has Usher syndrome herself, talked about educational options, entry into college, and programs and services available to individuals who are deaf-blind.

Psychosocial Issues

Ilene Miner, CSW

This session allowed parents to share feelings, fears, and aspirations. They had the opportunity to talk openly with two young adults with Usher Syndrome and ask them about their lives, their struggles and how they cope with day-to-day uncertainties about their lives and their vision.

Peer Discussion Groups

P. Molloy, J. Nuccio, J. Boardman, and P. Lago-Avery

Discussion groups, conducted in American Sign Language with voice translation for those whose primary receptive avenue is hearing, were co-led by adults who have Usher Syndrome. This was the first time that many participants saw someone like themselves in a leadership position. Issues that emerged during these groups related to self-esteem, fears about the future, fears about loss of independence, and concerns about parents.

Equipment Fair

Julie Anderson and Jim Bellanich from The Helen Keller National Center demonstrated new adaptive equipment for people who are deaf-blind.

The organizers gained a number of insights as a result of this weekend conference and a previous one held in 1995. These insights are summarized below.

Medical issues are complex. Presentation of these issues should be both formal and informal with time allowed for private discussions. Repetition of information is also important. Most individuals with Usher Syndrome and their families do not grasp all the implications of the disorder the first, or even the second time, they hear it.

A conference or retreat that focuses on self-empowerment begins with network building among consumers, their families, and professionals. Time should be scheduled for discussion of communication and attitudinal barriers that destroy trust.

It is important to talk openly about concerns related to Usher Syndrome. Many people feel that talking about depressing issues will have a negative effect upon those who have the syndrome and their families, but the opposite is true. Teens and young adults at the conference benefited from the opportunity to talk about their lives and to share fears and concerns that they won't be able to succeed or take care of themselves. Uncertainty about the future and vision loss were discussed openly with older adults who have Usher Syndrome who are coping with this uncertainty and exerting control over their lives. It became clear that individuals with Usher Syndrome need each other.

Madeline W. Appell, Paul M. Molloy and Ilene D. Miner are associated with the New York State 307.11 Project. Jerry Petroff is with the New Jersey 307.11 Project.

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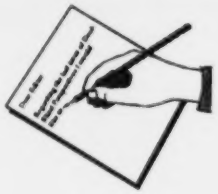


Letters to the Editor

Syndromes, Behavior, ... Winter 1996-97

Dear Editor,

I have been receiving this publication for about a year and wanted to let you know how much I enjoy it.

I work at a hospital that provides long-term care for children with multiple handicaps and medical needs. I began my job there as a special education teacher in the summer of 1994 fresh out of college with NO experience with "kids like these." Honestly, few people have had experience with kids like mine. I instantly fell in love with the kids and their challenges and am constantly searching for new information. We have kids with very rare genetic disorders as well as kids who have been the victims of accidents and abuse.

Your most recent issue with the article "Syndromes, Behavior, and Educational Intervention" (Van Dijk & Nelson) was very informative without getting lost in jargon.

Please continue to provide such good articles and I will continue to share your publications with my coworkers and my kids' parents.

Thank you,
Kimberly Hall

Deaf-Blind or Deafblind, or...?, Winter 1996-97

Dear Editor,

I cannot express it better than those experts did. The German association of parents of deafblind children (those with a vision less than 2% as blind is defined by German laws) decided to call it "TAUBBLIND" (http://selbsthilfe.seiten.de/taubblin.htm) without a hyphen. We applied to the European Communities Deafblind Secretariat in April 1994 to rename as follows: European Deafblind Network (EDbN). As EDN was already used we decided unanimously for the "small b" to accurately express what we feel.

It's always a pleasure to receive new ideas and recommendations by the Perspectives. To publish via WWW is really a gift for all those outside the centres of the field of research of deafblindness.

Thanks and regards,
Wolf-D. Trenner
Vice chair of FG Taubblinde e.V.
Bundeselternvertretung Deutschland

Dear Editor,

It seems to me that we are losing our perspective. Instead of focusing on the individual who happens to be dual sensory impaired, is our point of convergence labels and semantics?

In the great scheme of things, our numbers (persons who are deaf-blind, parents, siblings, professionals, significant others) are few in the movement to further the important and necessary causes of people who are deaf-blind. (You know the drill.) Why are we now challenged to become involved in a divisive exercise such as "to be or not to be?" What is the question?

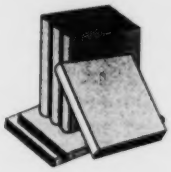
I have noticed that some of the folks who are proclaiming the word deafblindness as more appropriate, have yet to adopt 'people first language' n their dialogue. Please...let us not get caught up in wordsmithing, but instead, let us place our collective focus on persons and how we can assist them to become and maintain themselves as happy, productive, and satisfied human beings.

Sincerely,
Patricia J. McCallum
Mother of Jon (A person who happens to be deaf-blind)

Dear Editor,

Yes, I do agree with you about dropping the hyphen from the disability category "deaf-blind" There are good reasons to consider this change. You think that people that are deaf and blind should be called "deafblind" and not deaf-blind, So in your mind the word deaf-blind is not correct. I said that it's good sound to me so I want to put my organization name "Central Pennsylvania Association of the Deafblind." That's nice.

Thank you,
Zenola Tyson
President, CPADB



For Your Library

Basic Skills for Community Living : A Curriculum for Students with Visual Impairments and Multiple Disabilities

Levack, Nancy (Ed.); Hauser, Susan (Ed.); Newton, Lauren (Ed.); Stephenson, Pat (Ed.) / TSBVI. 1996/1997 edition. Austin, TX: Texas School for the Blind and Visually Impaired, 1996/1997. Length: xviii, 278pp + appendices

Details a curriculum created for students aged 6 to 22 who have visual impairments combined with other disabilities such as hearing impairment and significant developmental delays. Topics include assessment, community-based instruction, functional activities and developmental skills, developing an IEP, transition planning, teaching strategies, domestic activities, career education, recreation, communication, calendars, social skills and behavior management. Appendices include assessment and planning forms. Order from: Texas School for the Blind and Visually Impaired.

The Education of Dual Sensory Impaired Children: Recognizing and Developing Ability

Etheridge, David (Ed.) London: David Fulton Publishers, 1995. Length: xviii, 129

Deals with the education of dual sensory impaired children (impairments were either present at birth or acquired early) from birth to age fourteen. Topics include assessment, curriculum, communication, sensory stimulation, and the importance of the family. Order from: Sense.

Effective Practices in Early Intervention: Infants Whose Multiple Disabilities Include Both Vision & Hearing Loss

Chen, Deborah (Ed.) Northridge: California State University, 1997. Length: 294 pp + blank forms

Presents information developed as a result of a project at California State University, Northridge (the Model Demonstration Early Intervention Network serving Infants who are Deaf-Blind and their Families). Topics include program development, early intervention teams and collaboration, identification of infants who are deaf-blind, vision and hearing assessment and intervention, gross motor development in infants with multiple disabilities, medical interventions, beginning communication, and transition to preschool. Four videos were also developed as part of this project: "Vision Tests for Infants," "What Can Baby See?," "What Can Baby Hear?," and "Making the Most of Early Communication." For information about ordering

the manual, contact Deborah Chen at the Department of Special Education, California State University, Northridge, 18111 Nordhoff St., Northridge, CA 91330-8265, (818) 677-4604. Three of the videos are available from AFB Press. "What Can Baby Hear?" is available from Paul H. Brookes Pub.

Improving Access for Deaf-Blind People

Berg, Robert. Deaf-Blind Service Center. Seattle, WA: Deaf-Blind Service Center, 1995. Length: 17.30 mins.

A video intended for hearing and sighted people who work in recreational facilities, such as zoos and museums. It explains how to provide service and improve access to facilities for deaf-blind consumers. Order from: Deaf-Blind Service Center, WAT Alliance, Seattle, WA, (206) 323-9178.

Including Students with Severe and Multiple Disabilities in Typical Classrooms: Practical Strategies for Teachers

Downing, June E. Baltimore: Paul H. Brookes Publishing Company, 1996. Length: xiii, 196

Presents strategies for educating students with severe sensory and multiple impairments in public schools. The appendices include resources for providing technical assistance for teachers and information about augmentative communication systems.

Low Vision: A Resource Guide with Adaptations for Students with Visual Impairments

Levack, Nancy; Stone, Gretchen; Bishop, Virginia. 2nd ed., 2nd printing. Austin, TX: Texas School for the Blind and Visually Impaired, TSBVI, 1996. Length: xii, 264pp

A comprehensive guide to low vision for teachers, service providers, and parents with up-to-date medical, optical, and technical information. Contains information on functional vision evaluations, media assessments, assessments for distinguishing between learning and visual disabilities, and guidelines for planning and implementing programming that will enhance students' visual functioning. Also included is information on computer access and other electronic approaches to solve the challenges of low vision. Order from: Texas School for the Blind and Visually Impaired.

New Language of Toys: Teaching Communication Skills to Children with Special Needs

Schwartz, Sue; Miller, Joan E. Heller. Bethesda: Woodbine House, 1996. Length: v, 290

Shows parents how to use toys and other play activities to aid a child's language development. Includes children through age six. Order from: Woodbine House, Inc., 6510 Bells Mill Road, Bethesda, MD 20817, or by calling (800) 843-7323.

Planning Today-Creating Tomorrow: Guide to Transition

Steveley, Janet D.; Houghton, Joan; Goehl, Karen S.; Bailey, Brent R. Bloomington: Blumberg Center for Interdisciplinary Studies in Special Education, 1996. Length: iii, 52

A booklet containing information designed for individuals involved in transition planning for persons with deaf-blindness including those with other disabilities. Discusses components of transition planning, resource information, and transition terms and definitions. Order from: Indiana Deaf-Blind Services Project, Blumberg Center, School of Education 502, Indiana State University, Terre Haute, IN 47809.

Positive Behavioral Support: Including People with Difficult Behavior in the Community

Koegel, Lynn Kern (Ed.); Koegel, Robert L. (Ed.); Dunlap, Glen (Ed.) Baltimore, MD: Paul H. Brookes, 1996. Length: xvi, 510pp

Positive behavioral support is used to help people develop adaptive, socially desirable behaviors and overcome patterns of destructive and stigmatizing responding. It is typically used for people with developmental, cognitive, or emotional/behavioral disabilities, but can have more general applications. This book details case studies, research-based strategies, and discussions by various authors in the field of behavioral intervention. Geared towards behavior analysts, speech-language pathologists, educators, and child development professionals. Recommends strategies for reducing and preventing challenging behavior, encouraging family involvement, enhancing educational experiences, and expanding opportunities for social interaction.

Project Craft: Culturally Responsive and Family Focused Training

Chen, Deborah, Ph.D.; Brekken, Linda, Ph.D.; Chan, Sam, Ph.D. Baltimore, MD: Paul H. Brookes Publishing, 1997. Length: 60 mins.

This instructional video and its accompanying "Facilitator Guide" offer early interventionists an introduction to working with culturally diverse families. Promotes understanding of stereotypes and the media, cultural diversity, family values, relationship building, communication styles, and language acquisition. Families of children with disabilities from various cultural backgrounds and the professionals who work with them share their experiences and advice.

Reach out and Teach: Meeting the Training Needs of Parents of Visually and Multiply Handicapped Young Children

Ferrell, Kay Alicyn. / American Federation for the Blind. 4th Printing. New York: AFB Press, 1996. Length: 257

Designed to give parents guidance in raising and educating their visually and multiply handicapped children from infancy to young adulthood. It is meant to be used in conjunction with the Reach Out and Teach Reachbook. Practical information is supplied on diverse topics, such as how teachers teach, finding help, family issues, fine and gross motor development, daily living and communication, sensory and cognitive development, school years and beyond. The Reachbook is a workbook that provides tools to assess and record a child's development and to document parenting and teaching strategies and information gathered by parents from various sources.

A Sensory Curriculum for Very Special People: A Practical Approach to Curriculum Planning

Longhorn, Flo. London: Souvenir Press, 1995. Length: 242pp (Human Horizons Series)

Outlines a curriculum for each of the senses, using stimuli which can be varied to suit the age of the student. Designed to help teachers working with children with profound multiple handicaps combined with sensory and physical impairment. Suggests ways to integrate the sensory curriculum into a whole school program. Order from: Sense.

Student Portfolio: A System for Documenting the Strengths, Needs, and Abilities of Students Who Are Deaf Blind

Kansas Services for Children and Youth with Dual Sensory Impairments. Topeka, KS: Kansas State Board of Education, 1996.

A student portfolio is a collection of work, videotapes, interviews and other items documenting a student's abilities. It is used primarily with students with dual sensory losses. The purpose is to share information about an individual who is moving from one setting to another and can be used as an assessment tool within the education or transition planning process. This report includes a variety of forms to be used in the creation of a portfolio. Subjects include demographic data, preferred learning styles, MAPS summaries, student preferences, background maps, communication and educational summaries, and residential and vocational histories.

Tangible Symbol Systems

Rowland, Charity, Ph.D.; Schweigert, Philip D., M. Ed. / Oregon Health Sciences University - Portland Projects. Rev. ed. Portland: White Horse Studios, 1996.

A new version of the original video, "Tangible Symbol Systems," which was first produced in 1990. It illustrates communication options for a broad range of individuals of all ages who are unable to communicate through speech or manual signs. The instructional process involved in implementation of a tangible symbol communication system is illustrated. Parents and teachers are interviewed and case studies of 5 children over various periods from 4 months to five years are followed. The children shown are variously: deaf-blind, deaf, developmentally delayed, orthopedically impaired, and developmentally delayed with impaired vision. The video is accompanied by a manual. Based on Jan van Dijk's work with deaf-blind children, the techniques are also suitable for individuals of all ages with cognitive and/or severe communication deficits due to other disabilities. Can be ordered from Communication Skill Builders, 555 Academic Ct., San Antonio, TX 78204-2498, (800) 228-0752.

Teaching Students with Visual and Multiple Impairments: A Resource Guide

Smith, Millie; Levack, Nancy. / TSBVI. Austin: Texas School for the Blind and Visually Impaired, 1996. Length: xxii, 524pp

A resource guide for teachers of students with visual and multiple impairments. Topics include: best teaching practices, special needs of students with visual and multiple impairments, biobehavioral state management for students with profound impairments, and screening of infants and toddlers. A section on students with deafblindness and multiple impairments includes information on meeting this population's needs, screening, assessment, and communication strategies. Assessment tools and sample forms for planning an IEP are appended.

Videotape Protocol for Developing a Student Resume: Employment Skills and Work History

Wiley, David. / TSVBI Deafblind Outreach. 1996. Length: 3pp (SEE/HEAR, vol. 1, #3, Summer 1996, pp.14-16)

Students with deafblindness or who have visual impairments and other disabilities can use videotape resumes and profiles to show prospective employers and employment advocates a picture of the students' abilities and preferences by illustrating activities, routines, strategies for instruction and support, job activities and work-related skills. A device for planning and making a videotape is included.

When Hearing Loss and Retinitis Pigmentosa Happen Together: Meeting Educational Needs

Pennsylvania Department of Education, Bureau of Special Education, Instructional Support System of Pennsylvania; Distance Learning Center. Gibsonia, PA: Distance Learning Center, 1996. Length: 157 min.

A video aimed at teachers of deaf students. It begins with a good overview of Usher syndrome. Presenters talk about ways to check for Usher in the school environment and what to do if one suspects a student may have Usher. Teaching suggestions are offered. Funding sources, possible service providers, and support groups are discussed. A sign language interpreter signs throughout the video. May be ordered for $12.00 from Allegheny Intermediate

Unit, Distance Learning Center, 5347 William Flynn Highway, Route 8, Gibsonia, PA 15044-9644.

Competencies for Teachers of Learners Who Are Deafblind

McLetchie, Barbara, A. B.; Riggio, Marianne. / Perkins National Deaf-Blind Training Project. Watertown, MA: Perkins National Deaf-Blind Training Project, 1997. Length: 17pp

Teachers of deafblind children and youth, must have specialized competencies in order to meet the complex and unique needs of their students. Areas and knowledge delineated here are the outcome of a collaborative process involving university faculty and 307.11 project directors and are intended as a blueprint for personnel preparation programs in deafblindness. Areas of competencies discussed: general knowledge about deafblindness; personal identity, relationships and self esteem; concept development; communication; hearing-vision; orientation and mobility; environment and materials; and professional issues. A copy in large print is available.

I'm Moving on: This Book Will Help Me as I Move on into my Community

Trujillo, Toni (Ed.); Tavarez, Trudy (Ed.); Rubald, Tim (Ed.); Roach, Wanda (Project Coordinator) / New Mexico Deaf-Blind Services Transition Project. Santa Fe, NM: New Mexico Deaf-Blind Services, 1996. Length: 51pp

A manual designed as a personal record book or portfolio for dual sensory impaired individuals who are transitioning into community life. Included are forms to document the individual's mode of communication, favorite persons and places, medical and health issues, and prized possessions by photographs and/or video. With this manual, individuals in transition can inform new acquaintances and staff about his or her life experiences and needs. It is intended to be used in conjunction with "Moving On, Helping Individuals with Deaf-Blindness Move Successfully into the Community: A Manual for Transition Planners." Order from: New Mexico Deaf-Blind Services, 1060 Cerrillos Rd., Santa Fe, NM 87503, (505) 827-6707 for $20.00 plus $5.00 shipping. The companion manual for transition planners is available separately.

Ordering sources:

Paul H. Brookes Publishing, Co., P.O. Box 10624, Baltimore, MD 21285-0624

Texas School for the Blind and Visually Impaired, 1100 W. 45th St., Austin, TX 78756-3494, (800) 638-3775

AFB Press, Eleven Penn Plaza, New York, NY 10001, (800) 232-5463

Sense, 11-13 Clifton Terrace, London N4 3SR, England, (0171) 272-6012

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1997 National Conference on Deafblindness

The Individual in a Changing Society
June 6-9, 1997
Washington Hilton and Towers
Washington, D.C.

This conference will focus on the needs and rights of people who are deafblind and how these needs and rights will be affected by a changing society. The conference will address a wide array of issues confronting infants, school-age children, and adults who are deafblind, their families and the professionals who serve them.

For more information, contact

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No registrations will be accepted after May 31.
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